

Factors influencing  
delay and compliance  
to treatment among tb patients  
in Okhaldhunga, Nepal



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February 2006

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## 1. Definitions

- WHO: World Health Organization.
- CMA: Community Medical Assistant (15 months education).
- VHW: Village Health Worker (6 months education).
- Total delay: From the onset of symptoms till the time of diagnose.
- Patients' delay: From the onset of symptoms till the first visit to a health care provider.
- Health providers' delay: From the first contact with any health care provider till the diagnosis of tb.
- Low income countries: Defined according to the World Banks' list on [www.worldbank.org](http://www.worldbank.org).
- Defaulter: One who does not meet for treatment for 60 days.
- Failure: When a patient remains smear positive or become smear positive after adequate therapy for five months or more.
- Late patient: A patient who does not show up for treatment for 2 days.
- Compliance: Willingness to follow a prescribed treatment.
- Transferred out: When a patient is moved from one district to another during the treatment.
- PTB: Pulmonary tuberculosis.
- BNMT: British-Nepal Medical Trust.

## 2. Introduction

Tuberculosis (tb) is one of the greatest public health problems in the world. One third of the world's population is infected with the tb bacterium, and one new person is infected every second. Even though tb is a curable disease, there was 1,75 million deaths due to tb in 2003.<sup>1</sup> 95% of these occur in the developing world. The number of tb cases is increasing alongside the HIV-epidemic.

To deal with this problem, WHO started the DOTS strategy in 1993. DOTS stands for directly observed therapy short course. The strategy consists of five key elements:

1. Government commitment to sustained TB control activities.
2. Case detection by sputum smear microscopy among symptomatic patients self-reporting to health services.
3. Standardised treatment regimen of six to eight months for at least all sputum smear positive cases, with directly observed therapy for at least the initial two months.
4. A regular uninterrupted supply of all essential anti-TB drugs.
5. A standardised recording and reporting system to allow assessment of treatment results for each patient and of the TB control programme overall.

Despite good results from DOTS, the incidence of tb increases in the world.<sup>2</sup> There could be several reasons for this. The main reason is the HIV infection. Most of the increase in tb cases is in Africa. The combination of HIV and tb in a country leads to mutual speeding of the diseases. In Africa, HIV is the single most important factor determining the increased incidence of tb in the past 10 years.<sup>3</sup> In countries where tb is not increasing, WHO's goals for detection rate (70%) and cure rate (85%) is still not reached.<sup>1</sup>

One of the reasons for the goal for detection rate not being reached is delay to treatment. Detection of new cases is now based upon passive case finding. Passive case finding relies on suspected tb cases to present themselves to health services.<sup>4</sup> Patients delaying in presenting themselves have been found to be a challenge. Active case finding is not found to be cost effective and it is difficult to carry out on a large scale. Delays in the diagnosis of tb exacerbate the disease in affected individuals, increase their risk of death and prolong the period of time they are infectious<sup>5</sup>. It has been estimated that an untreated smear positive patient may infect on average more than ten contacts annually, and over twenty during the natural history of the disease until death.<sup>6</sup> Zafran et al has shown that delay in the detection of tuberculosis is the main factor contributing to death.<sup>7</sup>

The total delay to treatment can be divided into two main parts; Patients' delay and health workers' delay. Patients' delay is defined as the time from onset of first symptoms to first contact with a health provider. The health providers' delay is defined as the time from first contact with any health provider to time of diagnosis. The total delay to treatment has been found to be from 4,3 weeks in Ethiopia to 20 weeks in Tanzania.<sup>8,9</sup>

Another reason for the goal of cure rate not being reached is the emerging in drug-resistant tb. The most dangerous form of drug-resistant tb is the multidrug-resistant tb (MDR-TB). MDR-TB is defined as the disease caused by tb bacilli resistant to at least

isoniazid and rifampicin, the two most powerful anti-tb drugs. There are different reasons for drug-resistant tb occurring. Some of them are inconsistent or partial treatment, health workers prescribing the wrong treatment regime or unreliable drug supply.<sup>3</sup>

The last reason we want to discuss, is patients not complying with the treatment. Compliance rate has been increasing since the implementation of DOTS. In Nigeria they have found an increase from 20% to 73%.<sup>10</sup> Compliance rate influences the cure rate, but it is so far not high enough to reach the goal of cure rate. Compliance rate is an issue because poor patient compliance is believed to be the main cause of treatment failure and development of multi drug resistance.<sup>11, 12</sup> Multi drug resistance predicts higher mortality, and treatment completion is associated with improved subsequent patient survival.<sup>13</sup>

Reading some of the material written about DOTS and how it is carried out, we got particularly interested in how this actually affects the individuals being a part of the program.

The aim of this project was to look at the accomplishments of WHO's DOTS-strategy in low income countries. We wanted to increase our knowledge of how cultural, social, economical and geographic factors in a local society would influence the delay of tb-diagnostics and patients compliance during treatment.

In addition to study what the literature could tell us about these issues, we wanted to make our own research. In Nov-04 we went to Okhaldhunga community hospital in Nepal.

## 2.1 Nepal



The kingdom of Nepal lies in Asia, between India and China. It is known for its mountains, eight out of the ten highest mountains in the world lies in this country. But Nepal also has an area which is only 100m above sea level and has a subtropical climate, the Terai area. This area lies along the Indian border. We can divide Nepal's geography into three main parts, the Terai, the mountainous Himalaya and the hilly area in between. Most of the Nepalese lives in Terai or in the hilly areas.

Nepal is one of the poorest and less developed countries in the world. 40 percent of Nepalese lives below the poverty limit. For the last decade there has been a civil war in the country. The war is between the King and a communistic guerrilla group, the Maoists. Thousands of people have been killed in this war since the start in 1996.

27,6 million people live in Nepal. The human geography is a mosaic of different ethnic groups. There are somewhere between 25 and 100 different languages, but with Nepali as the official one. The main religion is Hinduism, but there are also many Buddhists, especially in the high Himalaya.<sup>14</sup> Some of the ethnic groups have their own religions.

We did our field study in Okhaldhunga, which is a district located in the mountains north-east of Kathmandu. The only means of transport which can help them communicate with Kathmandu and other cities is a plane. The airplane leaves the village only a few times a week, and it is so expensive that an ordinary farmer of Okhaldhunga would have to save for a long time to be able to pay for it. There are no roads, cars or bicycles in this district.

Okhaldhunga Community Hospital is located on a hillside in Okhaldhunga. There are 200 000 people who belong to it. At the time we were there it was run by United Mission to Nepal and they had been running it for 42 years. The patients cover 55% of the founding and 45% is covered by contributions. At the hospital they have a social office which tries to help the poorest patients with some of their expenses. In 2005 they had 16.335 patients at the out-patient clinic, 1.449 hospitalizations, 131 births, 1007 operations. (This information is given to us by dr. Erik Bøhler.)

People living in Okhaldhunga are mainly farmers. 95% of the inhabitants does not grow enough for living on their own field. This is why most of them work as porters or on

other people's land next to their own farming. If they work as porters, their daily salary is 50 to 150 rupees (which means 5-15 NKR). A caesarean section costs 12-15.000 rupees, this means about two hundred days' work. There is no export of food or materials from Okhaldhunga, this leads to bad economy. These days they are actually trying to change this. They have got coffee-trees which should be able to bare good fruit in a mountain district like Okhaldhunga. They are now trying to grow this to see if this is something they could export and which could give them an extra income.

There are different religions which people trust in; the Hinduism, which divides its followers into different casts, there are also some Buddhists, the Sherpas, and there are some who mix both Buddhism and Hinduism, the Rays. In addition to these there are a few Christians and other smaller religions.

Okhaldhunga has, as well as the rest of the country, been threatened by the civil war between the government and the Maoists. This threat has been increasing the last year.

### **2.1.1 TB in Nepal**

Tb is a severe public health problem in Nepal. In 2003 the incidence rate (pr. 100000) was 211. This makes Nepal one of the high burden tb-countries of the world.<sup>3</sup> 7-8000 people die annually of tuberculosis.<sup>2</sup>

They started DOTS in Nepal in 1996 and it reached Okhaldhunga in 1999. In Okhaldhunga the TB treatment is organised into two tb centres (Okhaldhunga community hospital and Rumjatar) and sixteen tb sub-centres (ten of the sub-centres are under the hospital and six are under Rumjatar).

The centres are mainly responsible for the diagnostics and the sub-centres mainly do treatment, but still, the only tb-hostel in the district is in the hospitals tb-centre. A tb-hostel is a building in the hospital where tb patients can stay free of charge. It has room for 8-10 people. They have no written rules to decide whether a patient can stay in the hostel or not, but who they allow to live there depends on:

- If they have a sub-centre close to their home or not.
- How weak they are.
- Whether or not they trust the patient to complete the treatment.

Those who stay at the hostel, lives there for the two months of the intensive phase.

The National Tuberculosis Program (NTP) for Nepal says that the responsibilities for the sub-centres staff are:

- To raise public awareness of tb.
- To identify tb suspects that comes to the sub-health post.
- To refer tb suspects to the health post, primary health centre or district hospital.

In the sub-health post in Okhaldhunga they are supposed to think of tb if a patient comes after at least two weeks with coughing. If they suspect tb, they should make a smear slide and send it to the hospital for diagnostics.

Tb patients can be divided into different diagnostic categories:

Category 1: New smear-positive patients, new smear-negative PTB patients with extensive parenchymal involvement, severe forms extrapulmonary tb.

Category 2: Previously treated smear-positive patients, treatment failure in cat 1,

Category 3: New smear-negative PTB (others than in category 1), less severe extrapulmonary tb<sup>15</sup>

The different medicines which are used in tb treatment are Isoniazid (H), rifampicin (R), pyrazinamide (Z) and ethambutol (E). There are different drug regimes for each category. The regimes used in Okhaldhunga are:

Category 1: HRZE daily for 60 days, intensive phase.

HE daily, but at home, 180 days.

If sputum still is positive after 2 months, they continue intensive phase for 1 month. They still have continuing phase for 180 days.

Category 2: HRZE daily for 60 days, intensive phase.

HRZE daily for 30 days.

If sputum neg. after 3 months, he will go to continuing phase for 150 days with HRE.

Category 3: HRZ daily for 60 days, intensive phase.

HE daily at home for continuing phase, 180 days.

(This information is given to us by Phaninra Dani, CMA working with the DOT program in Okhaldhunga.)

They have a recording and reporting system in Okhaldhunga. They use a card where they record every time the patient comes, one card for each patient. If the patient does not show up for his drug delivery, the hospital will send a letter, telling him to come. In Okhaldhunga they send about 2-3 letters like this each month.

They also have a meeting every fourth month where they invite all people working with tb in the district. This meeting is held by the British Nepal Medical Trust (BNMT). Here information about new case findings, cure rate, failure rate, defaulters etc are gathered. They spend some of the time discussing problems, and share their experiences. The national goal for case finding is 70% of the estimated burden of tb. The goal for treatment outcome is to cure 85%. Okhaldhunga results related to case finding and cure rate in 2003-4 are shown in table 1.

	<b>2003</b>	<b>2004</b>	<b>National goal</b>
<b>Case finding</b>	39%	45%	70%
<b>Cured</b>	76%	78%	85%

*Table 1. Okhaldhunga results related to case finding and cure rate.*



### 3. Methods

To fulfil our aims for this study we did a review of relevant literature on the topic, and in addition we wanted to make our own experiences in a field study. The field study was done in Okhaldhunga, Nepal, from mid November to mid December 2004. We interviewed the patients who were a part of the tb program at Okhaldhunga Community Hospital at the time we were there.

#### 3.1 *How we collected our data*

We brought two different interview guides to Nepal, one for patients and one for health workers. The interview guides are attached (attachment no. 1 and 2). Before leaving Norway we tried to work out a constructive interview. We read literature on tb from other low income countries, and were in contact with Dr. Erik Bøhler, working at Okhaldhunga community hospital. We based our interview guides upon these sources. The literature we used was searched using the words '*Tuberculosis*', '*Directly Observed Treatment*' and '*Compliance*' in Medline. Both authors read through the titles of the articles we found on these searches and rejected the ones that did not fit our assignment. Then we read through the abstracts of the remaining articles and chose those who fitted our object best. We also looked through the reference lists in the articles to identify further papers. Papers published after 1994 were included. It was a criterion that the studies were conducted in a low income country, after the implementation of DOTS. We excluded literature reviews and used only original articles.

Before leaving we thought that non-compliance was the main challenge in dealing with tb, and put a lot of effort in making relevant questions to this issue. After arriving Okhaldhunga, we understood that patients' and health workers' delay was a big a problem in this area. This is why we made some new questions and changed some of them we had.

When we came home we made a new search with the words '*Tuberculosis*', '*Directly Observed Treatment*' and '*Delay*' in Medline.

##### Patient interviews:

Data were collected from all adult tb patients who were treated at Okhaldhunga community hospital between 22/11-04 and 13/12-04. We interviewed eighteen patients. At the time of the interviews four lived at the hostel, four in the hospital and ten at home. We interviewed ten in the intensive phase and eight in the continuation phase.

The interviews were done by one of the two authors, all of them conducted through the same interpreter in Nepali. The interpreter was a 17 year old student, who lived in the neighborhood. She studied to be a CMA. The interviews were tape recorded and then written.

#### Health worker interviews:

Data were collected from nine health workers. They had different education and worked on different health posts/hospital. Most of the interviews were done on a tb meeting in Rumjatar. There we met one health worker at the time in a separate room. The setting was, except from a private room, the same as in the patient interviews. In addition to the health workers, we interviewed a social worker in BNMT. He worked in Kathmandu and was leading the meeting in Rumjatar.

We also wanted to know what the average inhabitant in Okhaldhunga knew about tb. To get an impression, we asked some questions to a random sample of people in the bazaar in Okhaldhunga. We interviewed 15 people all together. The questions are attached (attachment no. 3)

## 4. Results

Here is an overview of age and sex distribution of the patients we interviewed.

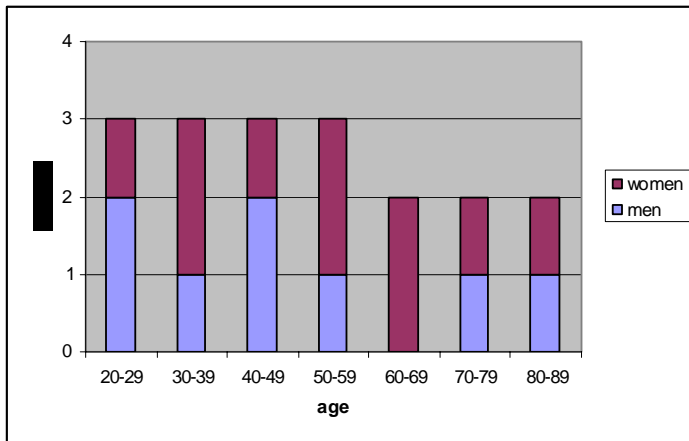


Table 2: Age and sex distribution

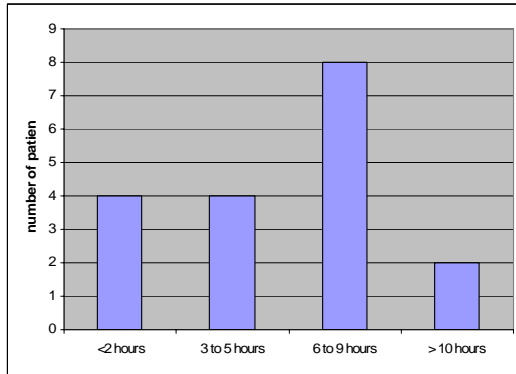
### 4.1 Delay to treatment

Many factors are associated with increased total delay. In the literature these issues are discussed: economy, stigmatization, distance to health care facilities, rural residence, knowledge, education, age, gender and the diversity of health care providers. From the interviews we did in Okhaldhunga we found three issues we thought were especially interesting, “access to health care facilities”, “knowledge, illiteracy and education” and “health providers’ delay”. We decided to look further into these issues.

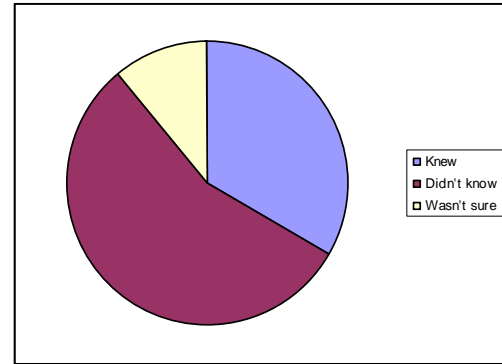
#### 4.1.1 Access to health care facilities

When the tb program is based on patients seeking help themselves it is obviously important that the treatment offered is accessible. It has to be accessible in the terms of distance, convenience and costs.

In Okhaldhunga the patients have to walk or be carried on narrow trails to health facilities. The distance the patients we interviewed had to walk to reach the hospital is illustrated in table 3.



*Table 3: Hours to walk from home to the hospital*



*Table 4: Patients knowledge about medicine being free of charge.*

As we can see ten out of eighteen had to walk more than six hours to reach the hospital. That is a considerably distance.

Since most of our informants were poor farmers, economy was an important issue. Their families had to struggle to get enough to eat during the year. The farming is done without any help from machines it is important that the whole family can participate. This leads to problems when one of the family members is sick. One of the questions in our questionnaire was “Is there any problems in your family in absence of you?” The answer to this question depended on the age of the patient. For the oldest patients this was not an issue, but for the ones with a family to provide for, it was not that easy. Many families did not manage all the work in the field when one of the adults in the family was absent. This was especially difficult in families where the mother was sick and the father worked away from home. That is not an unusual setting. None of the farmers we interviewed were able to feed the family from the croup the whole year. This is why some of the men work as porters and some work in Kathmandu or in India. One woman told us: “My husband is in Kathmandu that is why we have problems running the farm while I am here. My last daughter is five years old and lives with her grandfather now. She watches the farm during daytime.” Many of the others also told us about how their small children had to help out in the farm. Still they had problems managing.

Another important factor was the fear of costs. Like one man said: “If I go to hospital they ask me for money, and I have got none.” Ten of our eighteen informants did not know that the treatment was free of charge before they came to the hospital (see table 4). The ones who knew had been told by friends or heard it on the radio. One patient said: “I did not know before I came that it was for free, but I think maybe they will charge me for the sputum tests and the room.” Is that why you waited four months to go to hospital? “Yes, because of money problems. Being a farmer, how can I provide money for my health?” Two other patients also answered “money problems” when we asked why they waited for so long before they went to hospital. One of the health workers also mentioned this as a reason for delay: “Some do not come because they are afraid they will not be able to pay the costs.” This correlates well with the answers we got from people in the bazaar. Only five of the fifteen we interviewed there knew the treatment was for free. An

interesting finding in this context was that six of the ten health workers we interviewed thought that all patients knew the treatment was free of charge.

#### **4.1.1.1 Discussion**

Distance from home to health facility is shown to be an important factor for increased delay.<sup>16,9,8</sup> In Malawi Salaniponi et al interviewed 1099 patients with pulmonary tb.<sup>17</sup> When they looked at what places the patients preferred for the first visit to a health care provider they found that patients most often chose the health provider that was closest to home. In rural areas of Nepal this will often be a Damhi (traditional healer). There is often at least one of those in every village.<sup>18</sup> The health posts is more scattered around in the district.

Sixteen of our informants had to walk more than two hours to reach the hospital (table 3). In Ethiopia, Cambanis et al showed that a transport time over two hours were associated with longer delay to treatment. During the last years tb diagnosing and treatment is decentralized in many countries around the world.<sup>3</sup> That makes the access better, but to be successful it will demand better education of health workers in rural areas. As it is now, both a study performed by Wandwalo et al in Tanzania and one by Lienhardt et al in The Gambia have shown increased health workers delay in rural areas.<sup>9,5</sup>

Many of the patients we interviewed thought it was difficult to stay away from family and work for a long time. They had financial problems and problems running the farm. In rural areas, like Okhaldhunga district, with poor developed infrastructure and great distances it is not easy to go through with directly observed treatment with patients living at home. Different solutions to this problem have been discussed. One is to let family members deliver daily DOT. Another is to train community members in the village to deliver it.<sup>19</sup> In Okhaldhunga they are considering to try the community based DOTS. The family based DOTS is not an option at the moment. Like one of the health workers told us: "Not family based DOTS. If people are educated, family DOTS will work, but not all families are educated here in Nepal."

In another area of Nepal, Yamasaki-Nakagawa et al found that knowledge of the fact that treatment of tb was free of charge influenced the choice of which health provider to visit first.<sup>18</sup> This is why it is important that people get to know that tb treatment is free of charge. Many of our patients did not know.

We can not make any conclusions whether poor access to health facilities led to longer delay among our patients or not, but we have indications that long distances and peoples fear of costs increased delay, at least for some. In the literature several studies states that poor access leads to longer patients delay.<sup>16,9,8,18</sup> Wandwalo et al found that availability and accessibility of medical services is two of the most important determining factors for patients' action in Mwanza, Tanzania.<sup>9</sup> To decrease delay it is important that the population has good access to health care facilities. A study Cambanis et al did in Ethiopia concludes that most of the factors associated with patients delay were economic,

and if the health system had a better accessibility tb suspects would probably use it more often.<sup>8</sup>

#### **4.1.2 Knowledge, illiteracy and education**

One consequence of the low access to health care may be that people do not visit a health provider unless they are severely ill. Since tb not always gives severe symptoms in the beginning, it sounds reasonable that knowledge of tb and its symptoms would be important factors when it comes to delay.

In Nepal, and especially in rural areas like Okhaldhunga, the education level is low, and there are many illiterate inhabitants. In the patient interviews we did not really focus much on their knowledge, but in our interviews with the health workers we asked “what knowledge do the patients have of tb and its treatment before they start their treatment?” The answers we got were diverse. A couple meant that if some had cough and fever for more than two weeks they knew that it was tb suspect. Most meant that some knew a few tb symptoms, and others knew nothing about it. One of the health workers distinguished between educated and uneducated people. He meant that the educated ones and those who listened to radio knew about the symptoms, the uneducated knew nothing about tb. We also interviewed a social worker in BNMT. In 2003 BNMT conducted a review where they talked with people in 440 households in Okhaldhunga district. This review showed that only 23% knew about the symptoms and signs of tb. We did not ask our patients any questions of what they knew about tb before they came to hospital, but we asked some if they thought the symptom they had was due to tb. Only two of them had thought of tb before they came to hospital. This correlates well with the impression given by the health workers, who only had met a few patients who had asked if their symptoms could be tb.

Two of our patients said they waited two months before they went to hospital because they thought the cough was due to fever. They did not seek help before they were so weak that they could not work anymore.

We had a feeling that many of our informants did not know much about tb before they got ill, but since we interviewed them after they had been ill for a while this was not easy to confirm. When we asked people in the Bazaar if they knew any tb symptoms, only three of fifteen people knew any symptoms at all.

Three of the health workers linked low education to choosing a Damhi as the first health provider to visit. One linked low education directly to increased delay “Educated come to health post, un-educated come late”

We asked the health workers if they knew any myths about tb. Only one said that he thought people believed it was punishment from the Gods. The rest meant there were no myths related to tb anymore. One of them even said “The illness is due to a bacterium and if we take medicine the bacteria will die. The patients know this.”

#### **4.1.2.1 Discussion**

We did not ask directly about the patients' education or whether they were literate or not, nor did we focus on the patients' knowledge of tb in the interviews we did with them. This means that most of the information on these issues is from the health workers and from the impression we got from the interviews we did in the bazaar. The results would have been more interesting if we could compare them with information from the patients.

The literature indicates that the level of education correlates with patients delay<sup>5,9,20</sup> as do the illiteracy rate.<sup>21</sup> The education was low and the illiteracy rate was high in Okhaldhunga district and some of the health workers related low education to increased delay.

An important aspect in the literature is alternative explanation for the symptoms of tb. In a study Hoa et al did in Vietnam, 50% thought tb was due to hard work and 35% thought it was hereditary.<sup>22</sup> We did not find anything like this in Okhaldhunga. We asked the health workers if they knew any myths about tb, but only one knew any. Maybe there was none, maybe we asked the wrong questions. An interview with one of the Damhies would probably have illuminated this issue, but unfortunately we did not manage to get in touch with a Damhi.

The lack of knowledge to tb and its symptoms are not exceptional for Nepal. In a study from Ethiopia Demissie et al shows that 70% of the patients thought the symptoms would disappear by it self.<sup>16</sup> When Eastwood et al interviewed 30 tb-patients in The Gambia none of the interviewees knew the cause of tb and most denied having any knowledge to tb at all. Poor knowledge is shown to be associated with longer delay to treatment.<sup>8,9</sup> If the patients recognize the symptoms they have as tb-symptoms, the delay will decrease.<sup>21</sup> For this reason increased awareness in the population is an important factor to decrease delay to treatment. In Okhaldhunga they worked with this. The health workers went out in the villages and told people about tb. Information was also given in schools, put up on boards and broadcasted on Radio Nepal. Hopefully this will give a shorter patients delay in the future.

#### **4.1.3 Health providers delay**

Health providers' delay is the time from the patient first visits a health provider to the diagnosis is made.

In Okhaldhunga district there is one hospital and one health center run by doctors. The fifteen health posts and sub-health posts are managed by nurses, CMV's and VHW's. There are many traditional healers in this area. In general these Damhis (in Nepali) believes the illness comes from spirits in nature. The Damhis heal their patients by giving charms, praying to the Gods and some of them use herbal medicines.<sup>18</sup>

Among our eighteen informants only two reported that they had visited a Damhi as their first visit to a health provider. One of them, a 58 year old lady, illiterate, said: "I wanted to

get well without going to the hospital, so I went to the Damhi's house first. I did not get well and then I went to the hospital".

Among the health workers we interviewed it was a common opinion that many of the patients visit the Damhi before they seek regular health care. Some linked it to the patients' educational level. One said: "They who are not educated often go to The Damhi first. If there is no hope given from the health centers even educated people go to the Damhi."

A more common reason for increased health providers' delay in our group was wrong treatment in the health posts. Seven out of eighteen had visited a health post before they came to the hospital. There they got medicine for pneumonia or other diseases. Only two of them were recommended by the health workers in the health post to go to the hospital when the medicines did not help them. One 81 year old woman said: "I got medicine from the health post a year before I went to the hospital. They gave me Paracetamol and other medicines. I did not take my medicine regularly at that time. When I felt better I stopped, when I got ill again I went to the health post and got medicine again..."

#### **4.1.3.1 Discussion**

In some studies, the health providers' delay is reported to be longer than the patients' delay,<sup>5,23</sup> in other surveys patients' delay is much longer.<sup>16,9</sup> One reason for this diversity can be that when patients' delay is long the symptoms are more severe when they seek help. Then it is easier for the health providers to think of tb. This may correlate well with the fact that patients with haemoptysis experience shorter delay than patients with other symptoms.<sup>16,5,23</sup> In our study we did not really look into these issues. We found that for some patients the health providers' delay had been long, but we do not know if it was longer than the patients' delay.

Health providers are a heterogeneous group, traditional healers, pharmacists, private practitioners and other health workers with different amounts of education.

None of the patients we interviewed had visited pharmacists or private practitioners. Studies conducted in more urban settings in Vietnam, Ghana and The Gambia, where many medicines are sold over-the-counter, shows that many patients initially buy medicine for pneumonia etc from a pharmacy or a grocery shop. This gives a longer delay for diagnosis.<sup>19,5,23</sup> Initial visits to a private practitioner is also associated with longer delays.<sup>24,18,20,5,23</sup>

The longest health providers' delays are in several studies shown to be caused by visits to traditional healers.<sup>18,19,8,20,9,5</sup> That was also one of our two main findings. Some of the health workers we interviewed thought that almost all of the patients visited a Damhi before they came to hospital. This did not really match what the patients told us. There could be several reasons for this. It could be a coincidence, or maybe some of the patients tried to give us the "right" answers. To decrease the delay related to traditional healers, it is a possibility to increase the awareness of tb in the population, and teach that traditional



healers cannot heal tb, or they can make agreements with these healers so they send patients with tb-suspect symptoms to hospital. In Okhaldhunga they have already started to work on an agreement with the Damhies.

The other issue leading to increased health providers' delay in our study was wrong treatment in the health posts. Many of our patients had been to a health post several times before they came to the hospital and got diagnosed. It is understandable that tb not always is the diagnosis of choice in the first place, the symptoms could be vague, but it is important to reconsider the diagnosis when the medicine of choice does not work. It is important to increase the awareness of tb and its symptoms among health workers. In Okhaldhunga the BNMT-representative told us that they worked with increasing the tb-skills among the health workers. Among other things, they had a regular DOTS-training every third month.

Okhaldhunga is a rural area. Studies from Tanzania and The Gambia states that health providers' delay is longer in rural than in urban areas.<sup>9,5</sup> One explanation is that it is more usual to initially visit traditional healers in rural areas, another is that in rural areas the access to good health care is more limited, and the patients visits health providers with little or no education more often than in urban areas. It was very difficult to get educated people to work in Okhaldhunga. In the urban areas of Nepal it is more doctors and more educated health workers overall.

## **4.2 Compliance**

The high rate of patient's non-compliance with therapy has been identified as a major factor contributing to treatment failure and emergence of drug-resistant diseases.<sup>25</sup> WHO states that from a public health perspective, poorly supervised or incomplete treatment of tb is worse than no treatment at all.<sup>3</sup> When people fail to complete standard treatment regimes, or are given the wrong treatment regime, they may remain infectious. The bacilli in their lungs may develop resistance to anti-tb medicines. People they infect will have the same drug-resistant strain. While drug-resistant tb generally is treatable, it requires extensive chemotherapy (up to two years of treatment) that is often prohibitively expensive (often more than 100 times more expensive than treatment of drug-susceptible TB), and more toxic to patients.<sup>3</sup>

A lot of studies have discussed the compliance issue. A challenge in comparing data from the studies is that they have different definitions of compliance. One research defines a compliant patient as a patient who succeeds in conforming his illness behaviour to the medical regime,<sup>26</sup> other write about non-compliant patients as those who are defaulters. A defaulter is defined as patients who did not collect drugs for two months at anytime after initial registration<sup>25</sup> or those who fail to complete treatment.<sup>27</sup> In Okhaldhunga, Nepal, they defined a defaulter as one who did not meet for treatment for 60 days. They also had a group they called "late patients" and they were defined as those who did not show up for medicine for two days in the intensive phase.

Even though there are some differences in the definitions of non-compliant patients and defaulters, we will compare them as one group.

Reading the literature, we have found different reasons for patients being non-compliant. In our assignment we have chosen to focus on three important issues; stigmatization, economy and response to treatment. The reason for choosing these three, is that the literature, together with our field study, pointed out these to be the most important when it comes to DOTS and non-compliance. Other important factors for non-compliance, which we will not discuss, are how the distance to the hospital leads to non-compliance, how age and alcohol intake interfere and how inadequate attention from the health workers may lead to non-compliance.

Studies describe different numbers of non-compliant patients. A few found such a low number that most of the data they have is not significant,<sup>25</sup> even though these articles have been used.

#### **4.2.1 Stigmatization**

The definition of stigmatize is; “to characterize or brand as disgraceful or ignominious.”<sup>28</sup> Meulemans et al explain that “Stigmatization occurs when people are given a negative social label that identifies them as deviant, not because their behaviour violates norms but because they have personal or social characteristics that lead others to exclude them.”<sup>26</sup> The questions we asked to try to get an impression of the patients experiences with this were: 1. “Do you feel that your family supports you through this time?” 2. “Do your family and friends know that you have tb?” 3. “How do you feel about them knowing?” The first question was asked to get an impression of the people closest to the patients, if they accepted their sickness and actually helped them through the treatment. The second question we asked to investigate if the patient felt such a discomfort with his diagnose that he did not want to tell others. If the patient had not told his friends, we asked; “Is there any reason why you have not told them?” The last question we asked to try to make them explain if they felt embarrassed, ashamed etc.

All the informants felt supported by their family. Some gave examples of how they where supportive. One told us: “I feel fully supported, they bring me food from home.” We asked fifteen patients if their family and friends knew about them having tb, five out of these had not told them about it. They gave us reasons like: “In villageside they are all in their own way. They go to the field early in the morning, come back in evening. That is why they do not know what is happening with their neighbours” and “Nobody ask about my sickness. This is why I have not told them.” One of the patients, who had not told his friends, gave us a reason that might indicate that he feels stigmatized. He said; “My family knows about it, but my friends do not”. The reason he gave for not telling his friends was “I do not like to tell my friends about this. I am trying to escape from it”.

The last question was the one who gave us the most concrete information about stigmatization. Five of the sixteen patients we asked about how they felt about others knowing, told us about stigmatization. A women from the Gurungu caste said “I feel sad.

In our society neighbours and friends do not want to stay close to people with the tb diagnose.” Some others said; “I feel shame”.

While we were in Okhaldhunga there was only one of the tb patients on the programme who refused talking to us. The reason she gave was that she worked in a café. She said that if we interviewed her, everybody would know that she had tb. She was afraid this could lead to fewer customers in her café. These examples show that some feel the tb diagnose leads to stigmatizing. Still most of the informants had not experiences like this. When we asked; how do you feel about others knowing that you are sick, one man said; “They say; now you are well, nice. They do not hate me.”

We also asked some of the health workers if they thought the tb diagnose leads to social stigma for the patient. Six out of nine thought some patients experienced some kind of social stigma. One health worker said “They feel shame. When the patients come to the health post with tb symptoms the health worker tells them that it is probably tb, and you have to go to hospital and check the sputum. The patients feel sad and they do not want to tell anybody, they want to hide their disease.”

Our research in Okhaldhunga revealed that five out of sixteen of the patients told us that they felt stigmatized because of their tb diagnose, this is a rather big group. From whom we interviewed, we did not get the impression that this led to non-compliance.

#### **4.2.1.1 Discussion**

If patients really feel stigmatized because of their sickness, this might be an unpleasant thing to talk about. We came to Nepal as white Norwegians, interviewed patients who did not know us, and there were often spectators watching and listening to what the patients said. This might not be the best setting to get a trustable interviewing situation. We also used an interpreter, which might lead to misunderstandings. Despite this, we tried to ask some questions about this theme and hoped the patients would answer open and honestly. Five out of the sixteen we asked felt stigmatized. Going through the literature, we found some studies which had found stigmatization as a reason for non-compliance.<sup>11, 29, 26, 30</sup>

Goffman (1990) distinguished three different types of stigma. First there are abominations of the body, the various physical deformities. Next there are blemishes of individual character perceived as weak will, domineering or unnatural passions, treacherous and rigid beliefs and dishonesty. Finally, there are the tribal stigmas of race, nation and religion, these being stigmas that can be transmitted through lineage and equally contaminate all members of a family.<sup>26</sup> It might be hard to get an impression of what experiences a patient have to all these three types of stigma in a few questions. As discussed above, the setting for the interviews we made might not have been the best to get an honest answer about social stigma. This might also have been a challenge in some of the literature. A study done in Pakistan (Kaona et al) claims that patients being stigmatized have more irregular illness behaviour, and have problems following the treatment regime through to the end.<sup>26</sup> For the patient itself social stigma may lead to

unemployment, divorce, exclusion from social interactions and they might feel lonely.<sup>11, 30</sup>

It seems like women faces significantly greater stigma than men.<sup>25, 24</sup> A study done in south India (Balasubramanian et al) which looks at gender disparities in tuberculosis, states that; “women faced significantly greater stigma than men in terms of inhibitions in discussing their illness with family and friends (21% vs. 14%), feeling unwelcome to participate in social events (18% vs. 12%), or facing rejection due to their illness.”<sup>24</sup> In Nigeria (Erhabor et al) they found that ostracism or divorce could be some of the consequences for women with tb.<sup>25</sup> We did not look into this issue in Okhaldhunga, still all four patients who openly quoted that they felt stigmatized, were women.

There might be different reasons for women being more stigmatized than men. One reason is, of course, that they actually are more stigmatized. Another reason might be that a lot of the studies are based upon qualitative research methods. This kind of research may lead to more open acknowledgement of stigma by women than by men.

Even though some of the informants in Okhaldhunga said they felt stigmatized, a lot of them rejected it. Some of the informants had not told their friends or family about their disease, still they quoted not to feel stigmatized. The explanations they gave for this, we found hard to understand. They gave reasons like; nobody asks, and that they are too busy in the fields to have time to ask about other’s sickness. We probably need to know their cultural background better to understand these reasons for not telling friends about such a serious health condition.

#### **4.2.2 Economy**

Most of the people living in Okhaldhunga make their living from a small farm. There is no export of food or materials from this district, so the economy is low.

Because of the rurality in this area, tb patients often have to stay at a hostel for the two months of intensive phase-treatment and walk long distances to pick up their medicine in the continuation phase.

To get an impression of the economical status of the interviewed patients, we asked 4 questions which could highlight this. 1. “Which occupation do you have?” 2. “Who do you live together with?” 3. “How many months a year are you able to feed your family from your field?” and 4. “Did you know that you do not have to pay for your tb medicine?”

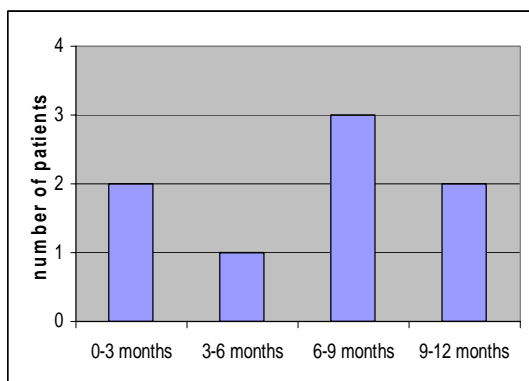


Table 5: How many months a year they can feed the household from the field.

Most of the patients we interviewed were farmers. We asked if there were any problems in the family in the absence of them. Lots of them stated that they had problems running the farm while they were in hospital. A man from the Sunuwar caste said: “Yes, it is a problem for my family that I stay here. My children have to work in the field. I want to go home.”

There were lot of others too who were worried for their children while they were on treatment. They had no other to run the farm in absence of them than the children themselves. A female Sherpa clearly states how difficult the economical situation is for a farmer. She says; “...being a farmer how can I provide money for my health?”

The mean number of months they could feed the household from the field was six (see table 5). To get enough food for living many of them had to work other places next to running their farm. The most common thing to do is working on other peoples land. One woman said: “We can feed our family six months a year from our field. The rest of the year we go to other houses and do farming there, this brings us an income.”

We interviewed those who were compliant, but it gave us an impression of what difficulties following the program lead to. These problems could be a reason for patients being non-compliant. Another fact we got from interviewing these patients were that a lot of them had to walk for hours to reach the hospital/health post where they could pick up their medicine in the continuation phase. From our interview it is easy to see that staying away from the field first in two months for intensive phase and then for some hours every week in the continuation phase, is a big economical sacrifice for these patients.

#### 4.2.2.1 Discussion

Staying away from work is mentioned as an issue in the literature as well as in Okhaldhunga. In Nepal they mentioned problems staying away from the field. There absenteeism is not a problem when it comes to earning enough money, but actually a problem of providing the family; having enough food to feed their children. The literature discuss' the absenteeism from work both as problems in the way of not having enough money to support their families and also the problem of retaining their jobs.<sup>27</sup> In Nepal all

informants except from one were farmers. The one with a different job worked with mechanic work in Malaysia. He explained that one problem was the economical situation by staying away from work; another issue was the fact that he might lose his job because of this. In a lot of low income countries they do not have a system with sick notes and sick insurance, this will for tb patients, in lots of occasions, lead to them losing their jobs while going through tb treatment. Even though people losing their job are not a big problem in Okhaldhunga, it might be a challenge when dealing with DOTS in more urban areas.

One of the issues highlighted in the literature as a factor leading to non-compliance is travelling time and costs.<sup>29, 25, 26, 19</sup> Some chose to drop out from the program and buy the medicine themselves instead of spending money on transport costs.<sup>25</sup> They look at both the problem with the actual transport costs and costs in means of time away from work.<sup>29</sup> In Okhaldhunga transport costs were not an issue, they all walked. Still one mentioned transport costs in form of having to pay for food on his way, he said “I have money problems, when walking I have to eat. I have problems coming here. I should be home in the field”. From this we can see that transporting costs might be both the actual money they pay for transportation, the money they lose staying away from work and even the costs for food while travelling.

The literature states that economical status is related to compliance, some articles even point's low economical status to be the main factor leading to non-compliance. Eastwood et al describes from Gambia that “inability to afford fares to attend clinics is probably the most important barrier to patients seeking and complying with treatment.”<sup>19</sup> A study done in Pakistan (Meulemans et al) concludes that those who are economically vulnerable, unemployed and poor will be the first to abandon the TB regimen.<sup>26</sup> From our study low economy was a noticeable factor, but we can not conclude that this is leading to non-compliance. The results might have been different if we got the opportunity to interview some from the non-compliant group.

### **4.2.3 Response to treatment**

Some patients feel worse after starting with tb medicine, some get side effects. These are different ways to respond to treatment, another way is to start feeling better. Now we will discuss how different responses to tb medicine can lead to non-compliance.

In our study we had four questions which could illuminate this problem. These are: 1. “Do you feel sick now”, 2. “For how long will the treatments last”, 3. “Is it important that you take your medicine every day”, 4. “Do you still have to continue taking medicine if you start to feel better”. The first question we asked to get an impression of their situation at that point. If they already started to feel better, it would be interesting to see if they still complied with their medicine. The second question we asked to know more about their knowledge about the treatment. We thought that it would be harder to be compliant to a treatment they did not know the duration of. The third question we asked to try to understand if they had any thoughts of reasons that could approve stopping taking their medicine. The last of these questions we asked to get an impression of the situation we

have found as the main problem in some of the literature; what they would think about taking medicine if they started to feel better or healthy. Would they think of that as a good reason to stop?

Most of the patient we interviewed had already started to feel better. One said “I feel well now, I am now able to carry a lot”. We did not ask a direct question about side effects, but one patient said the medicines he took made him sick. We found it interesting to see that the group we interviewed was compliant to the treatment even though they already felt better. The fourth of these questions looks more directly into their understanding of the connection between them feeling better and the fact that they still have to continue the treatment. Everybody except one answered that they had to continue taking medicine even if they started to feel better. One female from the Yamang caste said “It is good for me to take medicine even if I do not feel sick anymore”. The one who did not answer positive to the question, answered “I do not know, if the doctor gives me, I will eat, if they do not, I will not”. One of the health workers we interviewed had a different impression about this theme. He said; “most of the patients complete the course, but we have now seen some defaulter cases. The reason of defaulter is that DOTS is a systematic treatment, in our village people are far from the health institutions. Sometimes they feel cured, and maybe they default.”

Our informants had good knowledge about the duration of the treatment. Nearly all of them answered “according to the doctor, I have to take the medicine for 8 months”. One patient answered “I do not know, as long as the doctor gives me medicine” and one said “I do not know how long I have to take medicine, nor how long I have to stay here. I want to go home”. These two are examples of patients that might end up being non-compliant, but they were compliant so far in their regime. The group we interviewed also had good knowledge about the fact that they had to take their medicine every day. A lot of them answered “Yes it is important to take the medicine every day for my health”.

#### **4.2.3.1 Discussion**

The conclusion of what we found in our patient interviews is that they have good knowledge both about the duration of the treatment, the fact that they have to take the medicine every day and even if they start to feel better. Most of them already had started to feel better, which underlines the fact that they continued taking their treatment even if they felt better. We did not ask any direct questions about how they would behave if they started to feel worse/ get any side effects.

The literature looks at side effects as one factor leading to non-compliance. We do not have much data on that from Nepal. The medicine of choice to treat tb is rifampicin, isoniazid and pyrazinamid. These medicines do all have side effects. Two side effects which are in common for all of them are liver failure and nausea.<sup>12</sup> Some patients do not get any information about the side effects and sometimes even the health workers do not have the knowledge to teach them about this. A study in Delhi, India (Kaona et al), states that twenty of forty default patients interviewed reported side effects of anti-tb drugs severe enough to precipitate default. Side effects in this particular study included:

giddiness, vomiting, restlessness, excessive sleepiness and lethargy.<sup>27</sup> Other studies find that 14-20 % of the patients who stopped taking medicine said the reason was reaction to drugs.<sup>31, 30</sup> An interesting finding when it comes to side effects in the literature was the health-workers knowledge about the same issue. In India (Jaiswal et al) found that when health workers were asked about the patient's side effects, they answered "No, there are no side-effects. Ask the patient to develop a strong will and continue with the treatment."<sup>27</sup> Imagine that a patient feels sick, comes to the health worker and gets tb medicine. After a while with this treatment he feels even worse. He goes back to the health worker and shares his problems. If he then gets the answer; these medicine do not make you worse, develop a strong will and continue the medicine. It would be easy to understand that such a treatment of patients could lead to mistrust to both the medicine and the health care provider and result in non-compliance. One of the health workers we interviewed said; "Some patients default because they do not eat good food and then they become weak. They think they are weak because of the medicine and that is why they leave the medicine". We did not ask this health worker if he knew about any side effects, but the statement he gives might indicate that he, as a health worker, is not aware of them. We think that better education of the health care workers could be one way to deal with non-compliance.

Not all studies conclude with a significant higher number of patients complaining of side effects in the default group than in the control group. In Madagascar Comolet et al found no factors related to the drugs themselves which were associated with default from treatment. They concluded that side effects are on the whole as frequent among the defaulters as among the controls, and are of fairly high frequency, between 40% and 50% in both groups.<sup>29</sup>

It would be interesting to know if the patients knew for how long the treatment was supposed to last. If they get side effects and neither know the symptoms nor for how long it will last, being non-compliant might be an understandable reaction. Inadequate knowledge about the duration of DOTS could be a cause or a consequence of low case-holding.<sup>31</sup>

Another response to treatment that leads to non-compliance, is the fact that the patients stop taking it because they feel better. Patients who commence treatment become non-infectious and already start to feel better after a few weeks.<sup>26</sup> An assessment of factors contributing to treatment adherence of tb done in Zambia (Kaona et al) concluded that the major and striking determinant of non-compliance was the patient beginning to feel better. In this study approximately 39,8 % of all tb patients on treatment did not adhere to their treatment schedules, when they started feeling better.<sup>30</sup> Other articles mention this problem as one of the reasons for non-compliance, without concluding with this as the main problem.<sup>11, 29, 27</sup> The literature we have studied is from low income countries. In countries like this "every penny counts". Continue paying the costs for the travel back and forth to the health clinic, and to continue to stay away from work because the health centre bad opening hours, is not something these patients will choose if they already think that they are healthy. If patients are not taught that completing the regime is important both for themselves to get healthy and for others, by not making resistant



bacteria, it might not be very hard to understand that they quit. Most of the patients we interviewed in Okhaldhunga knew that they had to continue taking medicine even if they felt better. This might be due to the lecturing on tb, which they had once a week in the hospitals waiting room, or it might be due to good teaching by the tb staff. Another reason for the good knowledge might be due to the fact that we only interviewed compliant patients. If our data from Nepal shows a correct picture of the situation in that district, it is probable that better teaching of the patients about this theme leads to higher compliance.

The last issue we want to discuss when it comes to patients being non-compliant because they felt worse; is the different terms they used. Some said they stopped because there were too many tablets to take and others because the medicine was too strong.<sup>27,30</sup> Some of these statements might be grounded in superstition. In India there is a belief that allopathic drugs are hot and produce a lot of heat in the body leading to side effects. The amount of heat is related to the number of tablets ingested per day.<sup>27</sup> This, together with the fear that the medicine is too strong, might indicate that there is some superstition which can lead to non-compliance. In Nepal some of the patients we interviewed went to Damhi who told them that they had a ghost problem instead of a bacterial problem. It is not known how big a problem this is. If it is a significant problem, it might be a difficult challenge. Dealing with a superstition which is grounded in the culture and/or religion is not easily solved.

## 5. Critical remarks and conclusion

In Okhaldhunga we only got hold of those patients who were under treatment at the hospital and who showed up, we did not succeed in finding any defaulters to interview. Another methodological problem is that our study group was small; we interviewed eighteen patients and ten health-workers. The setting for the interviews we made might not have been optimal; we used an interpreter, there were often spectators watching, and the patients did not know us and our background. Some of the patients had been on treatment for several months when we met them, so patients recall is a potential source of bias. The last methodological problem we want to mention is the fact that we did not know enough about the problems they actually faced in that particular area before leaving Norway. After a few weeks in Okhaldhunga we understood that delay was as big a problem as compliance. This is why we had to change a part of our interview guide half way through our study.

When we started to work with our results, we chose three issues under each category (delay and compliance) we wanted to look further into. These choices were made upon what we found most interesting and what the literature had most information about. It is possible that we left out issues that would have illuminated the aim for this study even better.

Our goal with this investigation was to get an impression of what challenges a tb-patient in a low-income country faces. Why do some delay seeking treatment and why do not all complete the treatment in the tb-program? Both in our study, where we interviewed tb-patients in a rural area of Nepal, and in the literature we found many factors who could illuminate this. The most important issues, as we saw it, were economical factors, poor access to health care, lack of knowledge, both among the patients and the health workers, and social stigma.

We will not make any conclusions on how to solve the problems with delay and default, but we will try to describe our thoughts about improvements that could be done.

The awareness of tb has to be increased, both in the community and among the health workers. If people know the symptoms of tb, the delay to treatment would probably be shorter. The health workers have to recognize tb-suspect patients and they have to have enough knowledge about tb, the treatment and the side effects so they can give the patients good information. In Okhaldhunga our experience was that the patients had achieved good information from the hospital about the treatment and the tb-program. We also think that increased awareness of tb will decrease the social stigma associated with this disease. Another important factor in this context is that increased knowledge will make people go directly to the hospital instead of visiting the Damhi first. In Okhaldhunga they tried to make an agreement with the Damhies so they would send tb-suspect patients directly to hospital. The poor access to health care facilities was a big challenge to some of the patients we interviewed. During the last years tb diagnosing and treatment is decentralized in many countries around the world. That makes the access better, but to be successful it will demand better education of health workers in rural

areas. It is shown increased health workers delay in these areas. In both literature and our field study economical problems seemed to be the most important challenge. This means that the most important health promoting measure in tb treatment is to fight poverty.

## 6. Acknowledgements

We want to express our gratitude to our adviser in Norway, professor Per Fugelli and to our adviser in Nepal, dr. Erik Bøhler, thank you both for being helpful and patient. We also want to thank Soni Rai, who acted as interpreter, for excellent work and Phandindra Dani for all the time spent teaching us about tb in Okhaldhunga. We wish to thank Kristin Bøhler for her friendliness and hospitality. We express our gratitude to all the staff at Okhaldhunga community hospital for your co-operation.

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